

Safeguarding the 'Future Diary' Encoded in the Human Genome _____ *by: Mark Willis*

The promise of DNA testing and gene therapies may transform medicine in the 21st century. But without thoughtful legal safeguards, promises could turn to threats on the long-standing tradition of privacy in the doctor-patient relationship.

That's what the "Genetic Age" will mean for all of us, according to George J. Annas, J.D., M.P.H., who presented grand rounds on the topic of "Genetic Privacy" in January at Miami Valley Hospital. His talk was held in conjunction with the eighth annual Law-Medicine Symposium sponsored by Wright State University School of Medicine and the University of Dayton School of Law.

One of the nation's foremost authorities on law and medicine, Annas is a regular contributor to the New England Journal of Medicine. Annas is the Edward R. Uteley Professor and Chair of the Health Law Department at Boston University (B.U.) School of Public Health and founder of BU's Law, Medicine and Ethics Program. He has served as an advisor to the National Institutes of Health and the Human Genome Project on legal and ethical issues related to genetic research and has drafted model legislation for a nationwide Genetic Privacy Act.

Annas defines genetic information as the type of information that is now being mapped by the Human Genome Project -- the sequencing of base pairs in human chromosomes. He does not include family histories or the results of biochemical tests for proteins in the body in his definition.

Some experts argue that the information contained in a person's genes is much like other medical information and needs no different privacy safeguards. Annas disagrees. "The genetic information contained in your DNA sequences is uniquely private, personal information. Therefore, it requires special privacy protection."

Most other medical information involves diagnosis of a patient's present conditions. Genetic information differs because it involves a patient's predisposition to disease and other health problems in the future. It involves probabilities rather than certainties. According to Annas, most patients today do not understand that distinction. "We don't really know how to describe a predisposition," he says.

The information encoded in a person's genes represent a "future diary," according to Annas. Paraphrasing the New York Times columnist William Safire, a diary is a private, personal record used to inform the aging self about the younger self. "Your DNA is a future diary that informs your younger self about your aging self," Annas explains. "You may not want other people -- your government, your employer, your school -- to know about your probabilistic future medical history."

The personal health information contained in such a future diary also applies to an individual's parents, siblings, and children. According to Annas, privacy protection of one's genetic information should also extend to one's family.

Does a doctor have an obligation to disclose the results of a patient's genetic tests to others in the family? Annas believes that such a legal obligation would jeopardize the privacy in doctor-patient relationships. "Individuals should feel a strong moral obligation to share such information with their family," Annas says. "It should not be a legal obligation, but a moral one."

A DNA sample itself, not just the results of its analysis, represents a future diary of genetic information. The privacy of DNA samples collected and stored in large data banks also must be protected, according to Annas. He notes that informed consent provided at the time a DNA sample is collected -- for a specific research study today, for example -- should not be construed as a blanket consent for the thousands of genetic tests that may be possible in the future.

"The right not to know may be as important as the right to know," Annas says. "That is a unique thing about genetic information."

Up to now, much of the public discussion about genetic privacy has centered on the possibility of discrimination by insurance companies and employers. According to Annas, there is a general consensus that employers should not use genetic information to decide whether or not to hire or promote workers. Similarly, most people agree that genetic information should not be used to disqualify individuals from health insurance.

"In a sense, your genes could be seen as pre-existing illnesses," Annas explains. "To see a genetic condition that hasn't manifested itself in the body as a pre-existing condition means that we all have pre-existing conditions because nobody has perfect genes. Everybody has genes that predispose."

Genetic privacy laws have been passed by a number of states including Ohio, but comprehensive federal legislation has not yet been enacted. Annas believes that such legislation should guarantee the individual's right to:

- determine who may collect and analyze DNA;
- determine the purposes for which a DNA sample can be analyzed;
- know what information can reasonably be expected to be derived from the genetic analysis;
- order the destruction of DNA samples;
- delegate authority to another individual to order the destruction of the DNA sample after death;
- refuse to permit the use of the DNA sample for research or commercial activities; and
- inspect and obtain copies of records containing information derived from genetic analysis of the DNA sample.

Annas's proposed Genetic Privacy Act with commentary can be found at the following Internet site:

<http://MED-SPH.BU.EDU/Depts/LW/DOCUM.HTM.z>